Mixed methods

Parents of non-verbal children with learning disability (LD) most commonly recognise their child's pain through vocalisations, social behaviour and facial expressions

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Lynn M Breau

Department of Psychology, Glenrose Rehabilitation Hospital, Edmonton, Alberta, Canada

Correspondence to: Dr Lynn M Breau, Department of Psychology, Glenrose Rehabilitation Hospital, 10230 111 Ave., Edmonton, Alberta, Canada T5G 0B7; lynnbreau@gmail.com

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Implications for practice and research

- When parents assess pain responses, using a numerical pain rating scale, in children who are non-verbal and have a learning disability (LD), they most often equate responses to pain extremes (scoring 0 or 10 accordingly) or at the midpoint (5).
- Children's pain responses change qualitatively with pain severity; reducing the content of current tools or developing alternative briefer tools to improve feasibility may reduce the validity of pain assessment in children who are non-verbal and have LD.

Context

Assessing pain in children who are non-verbal and have learning disability (LD) is challenging. Yet these children experience frequent and significant pain because of complex concomitant health conditions.[1] It is widely perceived that pain responses in these children are idiosyncratic and parents report that 'knowing' their child is an essential part of pain assessment.[2] However, standardised pain assessment tools have been developed and found to have good reliability and validity, suggesting this group of children have commonalties in relation to pain responses that can be observed and rated by health professionals. Solodiuk explored the relationship between parents' descriptions and assessment of their child's pain using the numerical pain rating scale (NPRS) with nurses' assessments. In addition, the correspondence between the behaviours described by parents and previously validated pain tools was investigated.

Methods

Fifty parents participated and described the responses their child typically displayed when not in pain and when experiencing acute pain, and equated those behaviours to the NPRS, which is graded 0–10. Descriptions were subjected to a summative qualitative content analysis. Five existing standardised observational pain tools were examined to determine whether they contained items equivalent to parents' descriptions. Pain behaviours were analysed quantitatively to evaluate whether pain severity and selected child characteristics were related to the predominant type of pain behaviour demonstrated by the child.

Findings

A total of 423 pain responses were recorded by parents; 21% described the absence of pain, 14% equated to NPRS point 5 and 18% with NPRS point 10. Seven behaviour categories were generated: vocalisations (39.4%), social (21.8%), facial expression (16%), physiological (7.2%), muscle tone (6.9%), activity level (6%) and self-injurious behaviour (2.7%). Parents' descriptions were represented best by the items contained in the Non-Communicating Children's Pain Checklist (NCCPC)[3], with 97.2% of their descriptions having a corresponding item on the scale. There was poor correspondence about the Pediatric Pain Profile[4] and University of Wisconsin Children's Pain Scale,[5] which included the least number of items representing descriptions provided by parents (68.1%). Pain severity, but few child characteristics, was related to the response type.

Commentary

Solodiuk described parents' impressions of their child's typical pain responses and how they related their descriptions to the NPRS. The findings should be interpreted with caution because children did not experience pain across all severity levels. Thus, parents had to speculate what they perceived their child's response would be at some NPRS points.

Nonetheless, the study does supplement current qualitative understanding of how children with LD display pain. Four of the findings are particularly useful: first, descriptions of pain behaviours were most often equated with the 0-point, 5-point or 10-point locations of the NPRS, suggesting parents tended to categorise responses at the extremes and midpoint of the NPRS. Parents may have difficulty in distinguishing subtle changes in response associated with linear increases in pain severity. This is important because treatment decisions are often based on ratings from a scale of 0 to 10, or their equivalent, and may be based on a single-point difference.

Second, most parents' descriptions were found in the comparison tools, supporting their validity. Not surprisingly, the NCCPC, which has the most number of items and was developed from parent interviews, was the most comprehensive. Third, few of the child characteristics were related to pain responses, supporting the development of standardised scales based on children's lack of verbal ability rather than on individual characteristics or diagnosis.

Finally, the importance of a comprehensive tool is highlighted because responses may change qualitatively as pain severity increases in this group of children. Although there is often a drive to shorten tools to improve their feasibility, tools with larger item sets may be more valid for assessing the range of responses an individual child shows as pain increases. Research focussing on alternate methods of using existing tools, such as parents rather than professionals using them in hospital, may be more important to improve clinical pain assessment, rather than efforts to generate alternative or shorter tools. In the interim, clinicians should continue to use standardised tools whenever possible.

Competing interests None.

References

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